MDDAC

SNAPSHOT REPORT 4:

Survey of Public Perceptions of Data Sharing for COVID-19 related purposes

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UKRI Arts and Humanities Research Council

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With special thanks to our reviewer, Joseph Newbold

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KEY RECOMMENDATIONS

The design of future data-sharing initiatives:

- **should be transparent about which organisations have access to what data and when**.

  Information should be made publicly available in an accessible form from the beginning of the data-sharing initiative to allow for informed decision-making. This information should also cover inter-organisation data sharing as transparency about the limitations of such data-sharing may also allay the public's concerns.

- **should avoid a "one-size-fits-all" approach**.

  Bespoke data-sharing initiatives and methods for communicating their design could be developed by understanding which social groups or demographics are most vulnerable to either being dissuaded from, generally undecided about, or resistant to data-sharing and why. Also, local versions could be implemented, rather than the design of the data-sharing initiative and the methods for communicating its design being the same nationwide. This would allow local/regional levels of government, such as local authorities, to utilise their understanding of and established relationships with local communities.

- **should provide options for how much data-detail to share**.

  The ability to choose between several 'levels' of detail in the data that is being shared would allow individuals to engage with the data-sharing initiative in a way that they are comfortable with. Clearly stating why sharing one level of data-detail would be more beneficial than another would also allow individuals to make an informed decision based on a greater understanding of the impact of their contribution.

HEADLINE FINDINGS

Our participants prefer to share data when:

i) the UK COVID-19 Alert level is higher,
ii) the data is anonymous, rather than identifiable,
iii) it is shared with a Public Health Body or the Local Authority, rather than a Commercial Company or their Regional Police Force
iv) it is Medical data being shared rather than Mobility data

- And so, **which organisations have access to what data and when is important to data-sharing decision-making.**

Grouping them based on the similarity of their answers, we found 7 clusters of participants within our data. When it comes to data-sharing, we found groups that are:

i) Dissuadable (mostly willing but can be unwilling, 19.8%, 199)
ii) Undecided (mostly 'neither willing nor unwilling', 6.5%, 65)
iii) Resistant to (mostly unwilling, 9.2%, 92)
iv) and would Opt-out (consistently very unwilling, 3%, 30)

plus 3 groups that are consistently willing to share (total 61.5%, 617)

- And so, **it cannot be assumed that the urgency of a global pandemic leads to people disregarding their concerns and engaging with data-sharing initiatives.**

We also found that i) the UK COVID-19 Alert level, ii) if the data is anonymous or identifiable, and iii) the organisation that the data will be shared with, all influence how much detail participants are willing to include in the data that they share. Further, the influence of these factors differs for Medical data and Mobility data.

- And so, **the decision-making behind how much detail to include in the data being shared is complicated.**

MOTIVATION AND BACKGROUND

Since the start of the COVID-19 pandemic, the UK public have been asked to share data in ways that have never been seen before, pertinent examples being contact tracing apps and the regular reporting of COVID-19 test results. These two data in combination are believed to be one of the most informative sources for understanding and predicting the spread of the virus - by knowing who is infected and who they are likely to have transmitted the virus on to - and thus indicate what mitigative approaches have most effectively minimized the spread of the virus[1]. But the urgency of the pandemic meant that there was little time to assess the public's willingness to engage with such COVID-19-motivated data-sharing. Not considering public opinion can lead to a lack of trust and adoption of a data-sharing initiative, as the public's response to a previous UK-based, non-pandemic, medical information data-sharing initiative evidences[2]. Therefore, knowing what factors (or "attributes") are likely to increase or reduce the general public's willingness to engage in a data-sharing initiative is paramount to its success.

In June 2021, we released an online survey and collected responses from a nationally representative sample of participants (n=1003). Our aim was to investigate how different attributes of data-sharing scenarios influence participants' willingness to share data. The attributes were: i) UK COVID-19 Alert Level, ii) whether data is anonymous or identifiable, iii) the organisation that it will be shared with, and iv) data type. We wanted to investigate their influence within a COVID-19-motivated data-sharing initiative, describing its purpose as "*to monitor if the current alert level, and its associated restrictions, is appropriate.*" This also allowed us to consider attributes more broadly, rather than those of a specific, already existing data-sharing initiative. In this vein, our initial descriptions of the data type attribute were somewhat ambiguous. In the survey, we first describe Medical data as "*information about your health that is gathered when visiting your GP, a hospital, or any other NHS or private health-service. Medical data can be essential health information (such as your weight and whether you smoke) or as detailed as your full medical record over several years.*" And we describe Mobility data as "*reflecting where you have been and when. It can be collected via a number of means, including mobile phone wifi data. Mobility data can be a list of countries you have visited or as detailed as the addresses of the buildings you have visited.*" Defining Medical data and Mobility data in this way allows for our findings to inform the design of future data-sharing initiatives that aim to manage public health during a pandemic more broadly in terms of the data that they might aim to collect. Later in the survey, we investigate how much detail participants are willing to share in their data, and in doing so, specify exactly what Medical data and Mobility data is being shared.

In this snapshot report, we describe our research method and survey design, report an overview of our participant demographics, and then go through the three main sections of the survey, summarizing the data analysis, results, and key findings. After which, we discuss the findings in more depth through making a series of recommendations for future data-sharing initiatives. Finally, we outline our intended future work.

RESEARCH METHOD

We deployed a survey of closed-ended questions using the software Qualtrics.[3] Recruitment was conducted via an intermediary, Prolific.ac.[4] On our behalf, they recruited a nationally representative sample in regard to Age (5 categories, each covering 10 years, from 18 to 58+ years), Sex, and Ethnicity (simplified into 5 categories) according to the UK 2011 Census from the Office of National Statistics.[5]

The survey was estimated to take 15 minutes (actual mean time was 17 minutes 30 seconds), and participants received £2.23 in renumeration, equating to a rate of £8.43 per hour (the UK's National Living Wage at the time was £6.56 for 18 to 20 year olds, £8.36 for a 21 to 22 year olds, and £8.91 for those over 23 years old)[6].

The survey included two sets of three attention checks. These attention checks looked very similar to the other survey questions, but their text gave instructions to be followed, e.g. '' Click 'Very Unwilling' '', allowing us to make sure that the participants were carefully reading the questions. At the start of the survey we informed participants that there would be attention checks and that their data would be rejected if they failed some of them. Participants received renumeration if they passed two out of the three attention check questions in each set.

We conducted iterative pilot testing to adjust and edit the survey. We performed two types of piloting. First, we piloted with 10 participants using the Think-Aloud method (a researcher observes the participant completing the survey and encourages them to provide a running commentary of what they are doing and thinking.[7]) Next, we piloted our survey on Prolific.ac. We conducted three pilots, the first with 24 participants, and the second and third each with 10 participants. Here, our focus was on the technical aspects, the labelling and structure of the data collected so that we could prepare for analysis and estimating the average completion time to ensure appropriate participant renumeration.

The survey was released at 11am on Monday the 14th of June at a time when there had been a total of 128,011 Covid-19 related deaths (within 28 days of first positive test) recorded in the UK[8] with 30.2 million people receiving two doses of a vaccine and a further 41.8 million receiving dose.[9] It took just over 48 hours to receive responses from a nationally representative sample of 1003 participants, the vast majority of whom submitted responses in the first 24 hours.

The study design was reviewed and approved by an ethics board at Northumbria University, Newcastle upon Tyne.

This report is an initial overview of the data collected via the main question types in our survey. Thus, our analysis merely scratches the surface of this dataset and the insights that we could gain. In the coming months we will conduct more complex statistical analyses and report these in future publications. We will outline our intended future work at the end of this report.

SURVEY DESIGN

Overview of the design of the 5 sections in our survey

To ensure a UK representative sample

Section 1. Demographic Questions

e.g. Age, Gender, Ethnicity, Country of residence

[Public Health Body] differs to reflect this answer, e.g. if Country of Residence is 'Scotland' then Level is 'Public Health Scotland'

Section 2. Introduce Attributes & Levels

Attribute	You are in Alert Level..	sharing..	with..	Your data is..
Levels	1 – UK is Covid-19 free	Medical data	[Public Health Body]	Anonymous – no name/address
	3 – social distancing required		Info-Insights	
	5 – Risk of NHS being overwhelmed	Mobility data	Regional Police Force	Identifiable – with name /address
			Local Authority	

Fictional company to avoid pre-existing brand biases

Ambiguous so we can investigate more in section 4 "Data Detail Sliders"

Section 3. Data Sharing Scenarios

Approach used known as ***Choice-Based Multiple Conjoint Analysis[10]***

In which of these two scenarios are you more willing to share your data? (19 questions remaining)

17 scenario comparisons with 2 likert scales each, plus 2 attention check scenarios with 2 attention check likert scales each

Scenario A		Scenario B	
We are in	Alert Level 5	We are in	Alert Level 3
You are sharing	Medical Data	You are sharing	Mobility Data
with	Info-Insights	with	your Local Authority
Your data is	Identifiable	Your data is	Anonymous

and used to monitor if the current alert level, and its associated restrictions, is appropriate.

and used to monitor if the current alert level, and its associated restrictions, is appropriate.

Scenario comparison pairs randomized and optimized to ensure maximal data through minimal questions

Tooltip appears when mouse hovers so participants can remind themselves what the attribute's levels are

Then ***Likert Scales*** to measure willingness in each scenario

Thinking about the scenario you chose, how willing are you to share your data?

Very unwilling	Unwilling	Neither willing nor unwilling	Willing	Very willing

Thinking about the scenario you didn't choose, how willing are you to share your data?

Very unwilling	Unwilling	Neither willing nor unwilling	Willing	Very willing

Section 4. Data Detail Sliders

'Move the sliders along each scale to indicate the amount of detail you'd be willing to share.'

Organisation changes with each set of sliders

Sharing **Mobility** Data with your **Local Authority**

No data	Countries visited and when	Towns/cities visited and when	Streets you visited and when	Buildings you visited and when	All destinations and routes taken
0	1	2	3	4	5

Anonymised data during Alert Level 1

Identifiable data during Alert Level 1

Anonymised data during Alert Level 3

Identifiable data during Alert Level 3

Anonymised data during Alert Level 5

Identifiable data during Alert Level 5

Notice that the scale changes to reflect the **data type**

Slider sets randomized

Sharing **Medical** Data with your **Local Authority**

No data	Covid-19 test results	Basic health information (e.g. BMI)	Current diagnoses and treatments	Medical records for the past 5 years	Medical records since birth
0	1	2	3	4	5

Anonymised data during Alert Level 1

Identifiable data during Alert Level 1

Anonymised data during Alert Level 3

Identifiable data during Alert Level 3

Anonymised data during Alert Level 5

Identifiable data during Alert Level 5

Section 5. Perceptions and Experience of COVID-19

Including "yes/no/I'd rather not say" questions about i) being a key worker, ii) having COVID-19, and iii) having an underlying health condition, and likert scale questions for i) risk of getting COVID-19, and ii) being seriously ill from COVID-19, e.g…

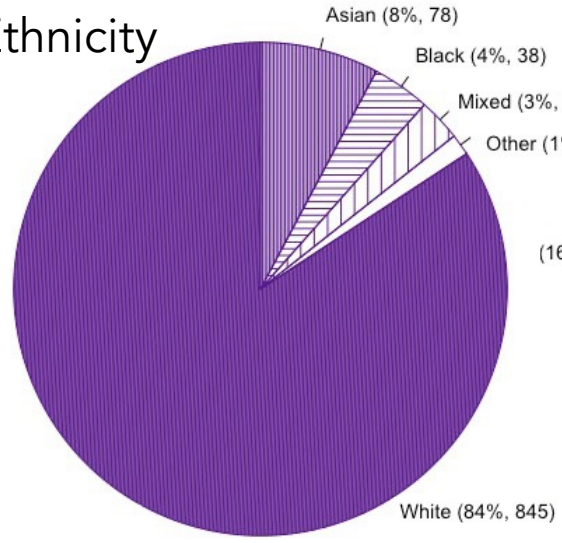
I feel my risk of getting Covid-19 is...

Very low	Low	Neither low nor high	High	Very high	I'd rather not say

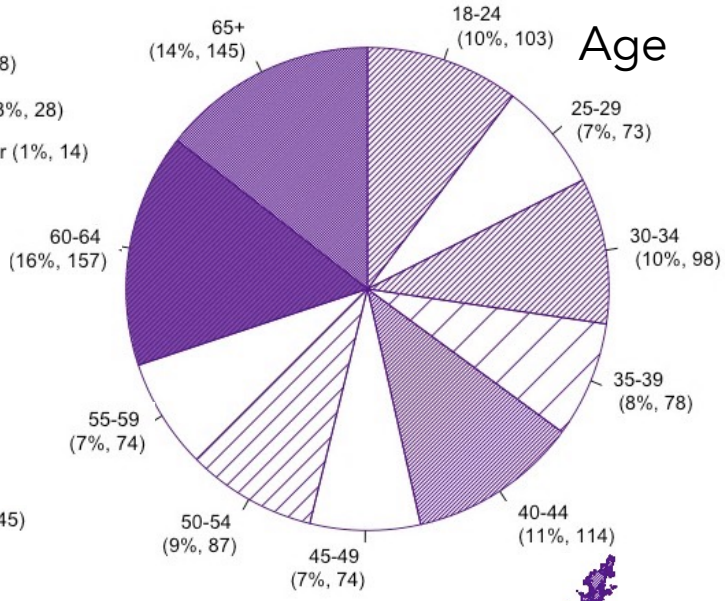
OUR PARTICIPANTS: *DEMOGRAPHICS*

Overview of data from *Section 1. Demographic Questions*

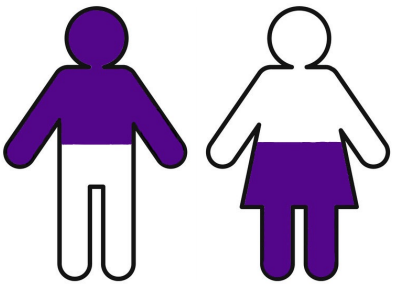
Ethnicity



Age



Sex



Male (49%, 487)

Female (51%, 516)

Income

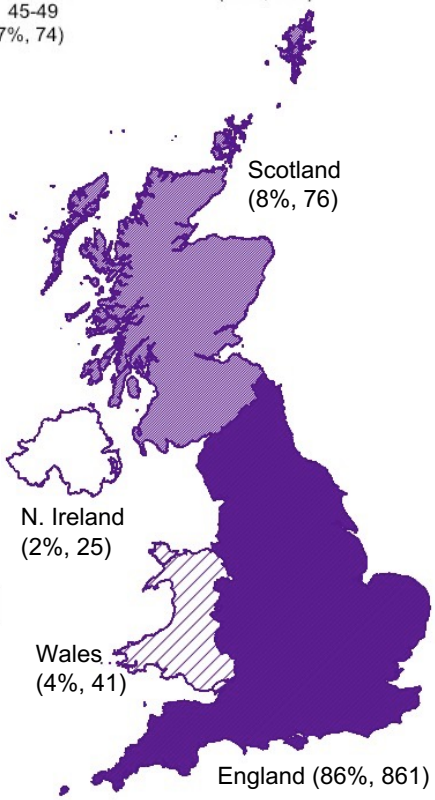
Participants considered their household income to be...

Below average (27%, 271) | Average (48.4%, 485) | Above average (24.6%, 247)

Education

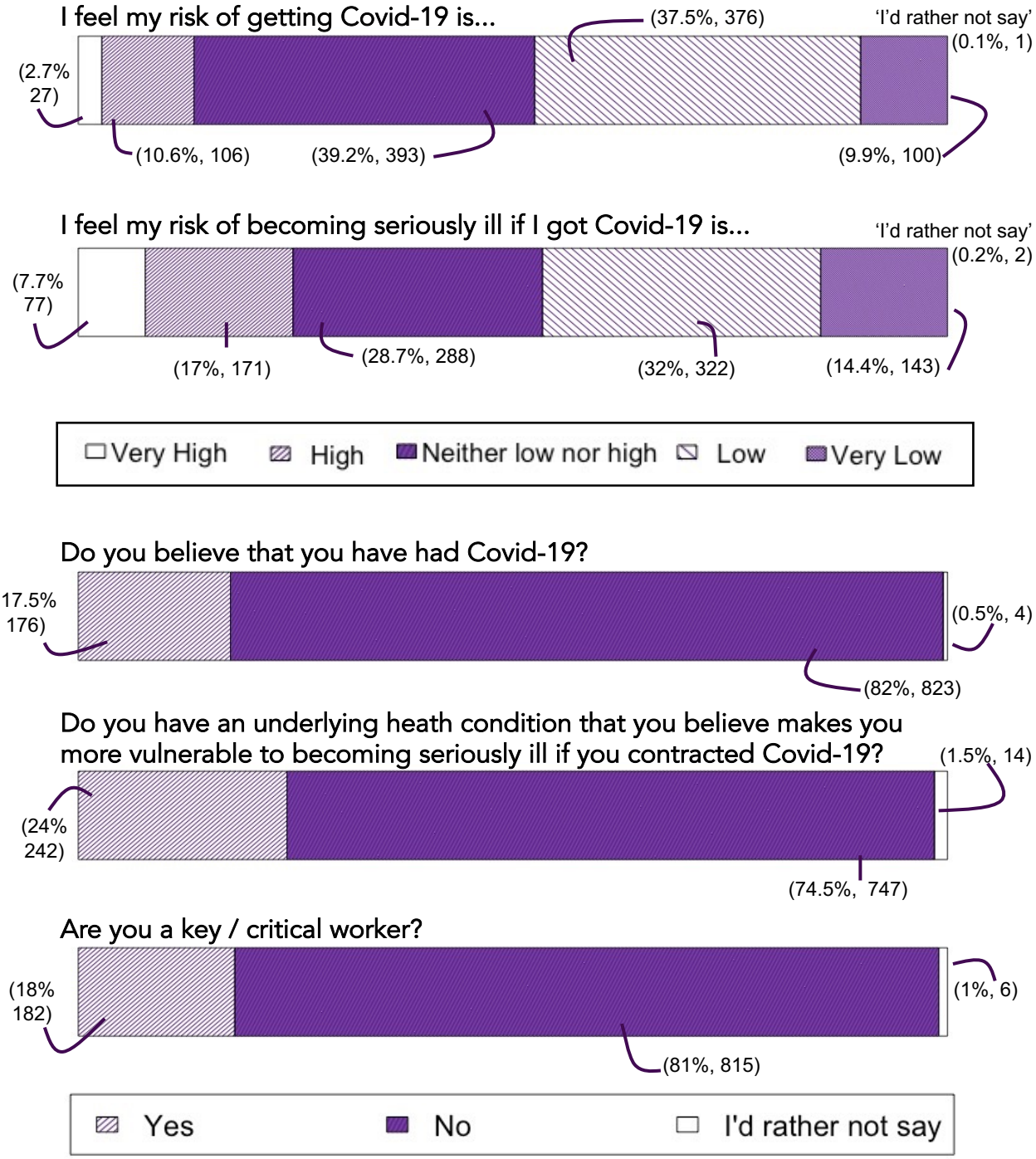
No formal qualifications (1.7%, 17)
A Levels/O Levels (24.5%, 246)
Graduate degree (20.3%, 204)
Secondary education (12.6%, 126)
Undergraduate degree (37.8%, 379)
Doctorate degree (3.1%, 31)

Country



PERCEPTIONS AND EXPERIENCE OF COVID-19

Overview of data from *Section 5. Perceptions and Experience of COVID-19*



CHOICE-BASED MULTIPLE CONJOINT QUESTIONS

Data collected in *Section 3. Data Sharing Scenarios*

KEY FINDINGS

Our participants preferred to share data in scenarios where:

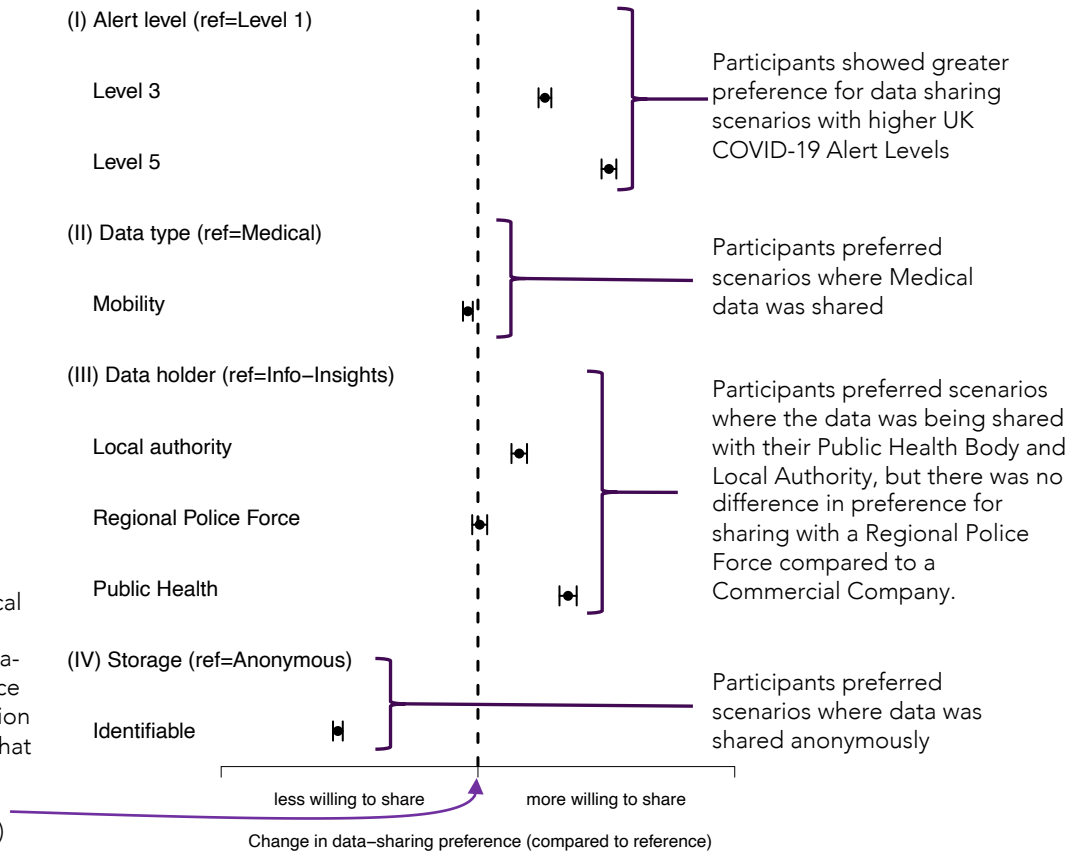
- i) the UK COVID-19 Alert level was higher,
- ii) the data was anonymous, rather than identifiable,
- iii) it was shared with a Public Health Body or the Local Authority, rather than a Commercial Company or their Regional Police Force
- and iv) the data was Medical rather than Mobility data

A reminder of the questions…

"In which of these two scenarios are you more willing to share your data?"

Scenario A		Scenario B	
We are in	Alert Level 5	We are in	Alert Level 3
You are sharing	Medical Data	You are sharing	Mobility Data
with	Info-Insights	with	your Local Authority
Your data is	Identifiable	Your data is	Anonymous
and used to monitor if the current alert level, and its associated restrictions, is appropriate.		and used to monitor if the current alert level, and its associated restrictions, is appropriate.	

Results: Change in preference



An interval overlapping with the dashed vertical line indicates no change in data-sharing preference between the option associated with that estimate and the reference option (e.g. (ref=Level 1)

WILLINGNESS LIKERT SCALES QUESTIONS

Data collected in *Section 3. Data Sharing Scenarios*

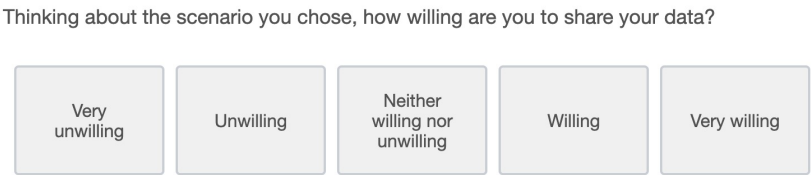
KEY FINDINGS

We grouped participants into clusters (via latent class modelling[11]) based on how similarly they answered the likert scale questions.
We found 7 clusters that reflect 7 distinct patterns of answering.
We have named these:

- The Committed to sharing, who consistently answered "Very Willing"
- The Eager to share, who consistently answered "Willing"
- The Discerning Sharer, who answered "Willing" and "Very Willing" equally
- The Dissuadables, who mostly answered "Willing" with some "Neither Willing nor Unwilling" and some "Unwilling"
- The Undecideds, who mostly answered "Neither Willing nor Unwilling" as well as "Willing" and "Unwilling" in equal proportion
- The Resistant to Sharing, who mostly answered "Unwilling"
- and The Opt-outers, who consistently answered "Very Unwilling"

A reminder of the questions…

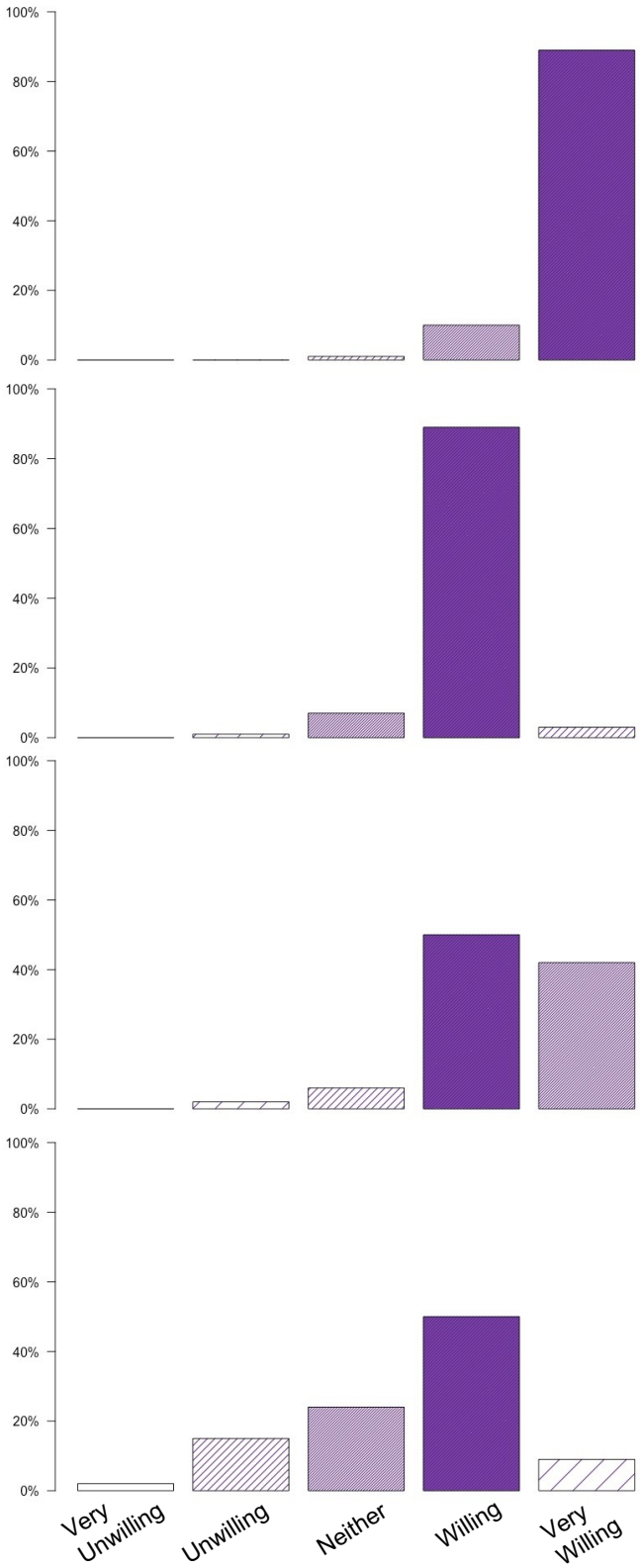
Having chosen the scenario in which they were more willing to share their data from two options, we then asked:



A couple of notes…

In the survey we also asked this question for the scenario that the participant did not choose, with a constraint that the willingness level is no higher than that for the chosen one. For example, if the participant clicked "Willing" for the chosen scenario then "Very Willing" would not be a clickable option for the not-chosen scenario. However, for the analysis herein we decided to only look at the answers that participants gave for the scenarios that they did choose because we wanted to explore whether participants expressed the same level of data-sharing willingness across all their chosen scenarios.

Results: Descriptions of the 7 clusters



The Committed to sharing
(15.3%, 153)

These participants almost always answered "Very Willing" under the scenarios that they preferred. This indicates that the attributes of their preferred scenarios had little influence over their data-sharing willingness.

The Eager to share
(20.5%, 206)

These participants almost always answered "Willing" under the scenarios that they preferred indicating a similar situation as was found in "The Committed to sharing" cluster.

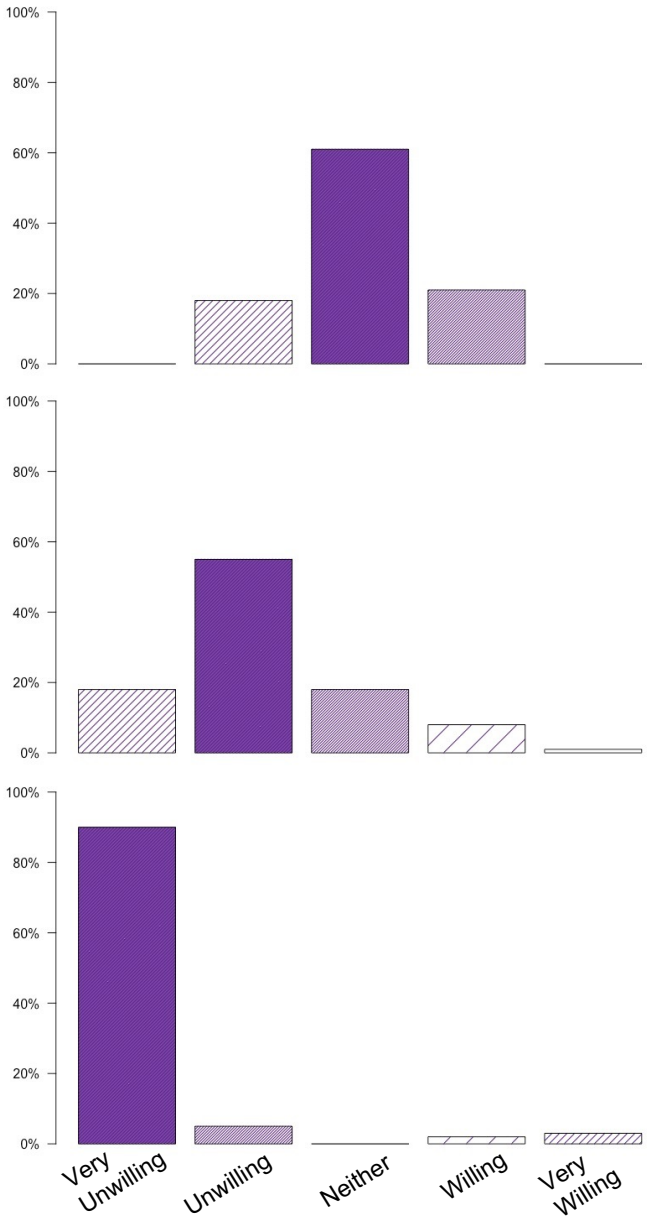
It may be that the participants in these first two clusters interpret "Very Willing" and "Willing" slightly differently, leading to a preference for which of these two answers to chose. Thus, their separation may be an artefact of this rather than reflecting two genuinely different clusters.

The Discerning sharers
(25.7%, 258)

Overall, these participants were willing to share their data, but some attributes in the data-sharing scenarios had an influence over how willing they were.

The Dissuadables
(19.8%, 199)

These participants were mostly willing to share data although in some cases they answered "Neither" or "Unwilling". This indicates that some of the attributes in the data-sharing scenarios 'put off' these participants from sharing.



The Undecideds

(6.5%, 65)

These participants mostly answered "Neither willing nor unwilling", and then "Willing" and "Unwilling" in near equal measure suggesting that they were mostly undecided. This indicates that the attributes of their preferred data-sharing scenarios were critical to their decision making.

The Resistant to sharing

(9.2%, 92)

These participants were mostly unwilling to share their data, however in some cases they answered "Neither" and also answered "Willing" occasionally. This indicates that there were attributes in their preferred data-sharing scenarios that persuaded them to share.

The Opt-outers

(3%, 30)

These participants almost always answered "Very Unwilling", indicating that the data-sharing scenario attributes had very little influence over their answer.

REFLECTIONS

The existence of these 7 clusters suggests that individual experience and opinion influences willingness to share data in addition to the data-sharing scenario attributes that we examined in our survey. It may be that the amount of information about a data-sharing initiative that is needed in order to become comfortable with engaging with it varies across these clusters. One way to address this would be to identify those who are currently not engaging but have the potential to (e.g. The Dissuadables and The Undecideds), ascertaining what aspects of the data-sharing initiative cause their hesitation, and then ensure that the information that they need to be able to make an informed decision is readily available.

DATA DETAIL SLIDERS

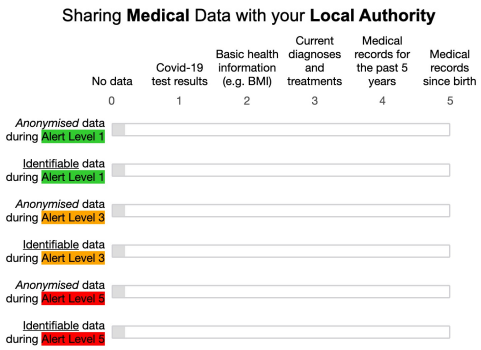
Data collected in *Section 4. Data Detail Sliders*

KEY FINDINGS

- All the Data Attributes appear to influence how much detail participants are willing to include in the data they share. The results of our statistical analysis (ordinal logistic regression[12]) support this observation, as all the levels of all the attributes are statistically significant ($p<0.05$).
- However, the patterns that we observe in the data differ across the two data types, suggesting that participants' decision-making is different when considering how much detail to include when sharing Mobility data and Medical data

A reminder of the questions…

"Move the sliders along each scale to indicate the amount of detail you'd be willing to share."

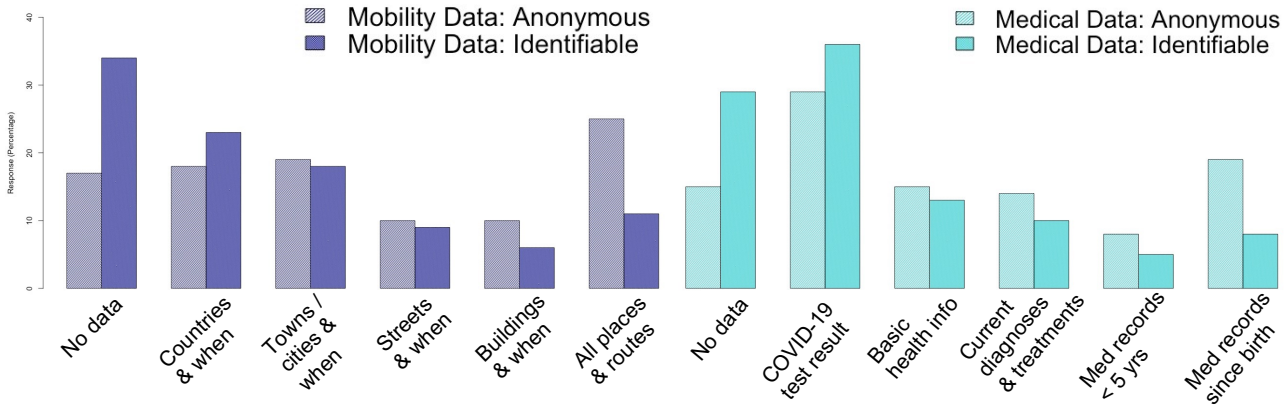


Results

Anonymous / Identifiable Data

More participants were willing to share more-detailed data when it was anonymous.
More participants would share less-detailed data if it was identifiable.

Across both forms of data, most participants chose to share their COVID-19 test results. Aside from this, more participants were willing to share more-detailed data when it was anonymous.

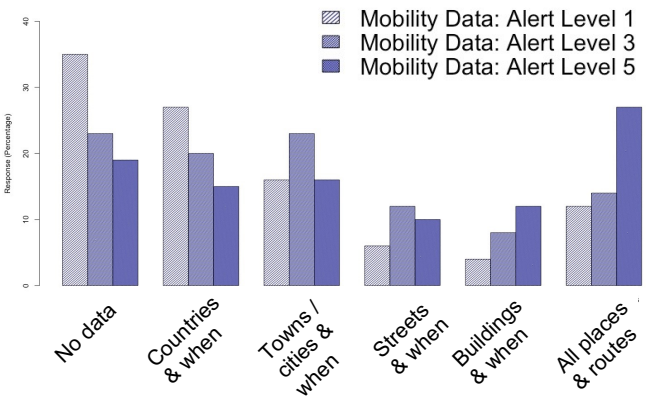


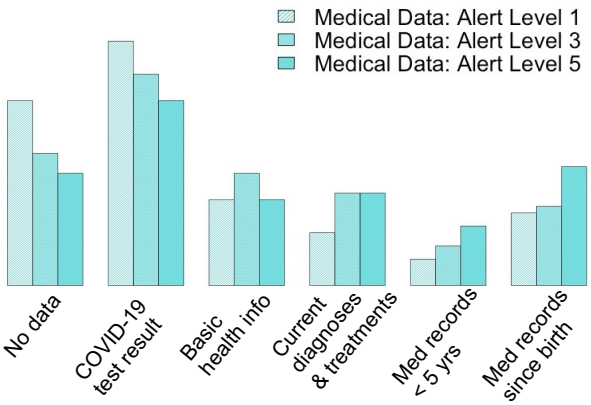
COVID-19 Alert Level

More participants were willing to share more-detailed data when the alert level was higher (level 5).

More participants would share less-detailed data if the alert level was lower (level 1).

Across all 3 alert levels, sharing COVID-19 test results was the most popular choice. Aside from this, more participants were willing to share more-detailed data when the alert level was higher (level 5). More participants would share less-detailed data if the alert level was lower (level 1).



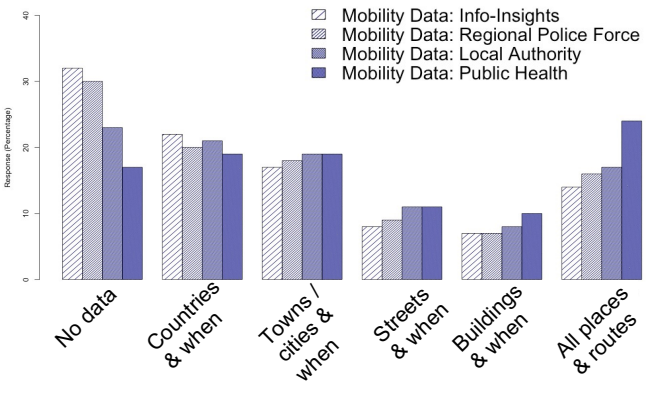


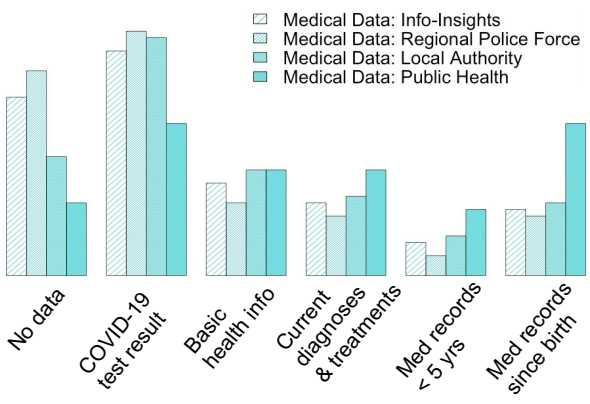
Data Holder

More participants were willing to share more-detailed data with their Public Health Body.

More participants would share less-detailed data with a commercial company ('Info-Insights') or their Regional Police Force.

Across three of the data holders, most participants chose to share their COVID-19 test results. The exception is Public Health Bodies - the same number of participants chose to share their COVID-19 test result as those who chose to share all their Medical records since birth.





RECOMMENDATIONS

Our first recommendation is that the communication of the design of data-sharing initiatives should be transparent about which organisations have access to what data and when.

Our survey's choice-based multiple conjoint questions highlight the importance of who the data is being shared with. For example, our participants preferred scenarios where the data was being shared with their devolved nation's Public Health Body or their Local Authority over their Regional Police Force. Furthermore, there was little difference in preference for sharing with their Regional Police Force and a commercial company. A previous OMDDAC report includes an outline of the risks and challenges surrounding police services requesting access to identifiable test and trace data for enforcement purposes[13], and it may be that our participant's concerns reflect these. As is also stated in this previous report, there is limited information in the public domain of exactly how such data is shared, used and stored.

Therefore, in the future it would be beneficial for information about data-sharing initiatives to be available to the public in an accessible form from the outset in order to allay concerns and allow informed decision-making. Specifically, this information should be easy to find and understand. This information should include, at a minimum, what data is being collected, when, and if it will be stored with identifying information, as our analysis found these attributes of a data-sharing scenario to also be pertinent to decision-making. Further, it would also be beneficial to include how and why an organisation is collecting data, and how it will be used and stored. In addition, details of inter-organisation data-sharing (e.g. a Public Health Body sharing data that it holds with the police), the limitations on such data-sharing, and what governance measures will be in place should also be publicly available.

Our second recommendation is that the design of future data-sharing initiatives should avoid a "one-size-fits-all" approach.

Our findings evidence that it cannot be assumed that the urgency of a situation such as a global pandemic is pressurising enough for the public to disregard their concerns and engage with data-sharing initiatives. While we found that our participants showed greater preference for sharing data as the COVID-19 alert level increased in our Choice-Based Multiple Conjoint Analysis, our cluster analysis of the Willingness Likert Scale data revealed groups of participants who are vulnerable to being dissuaded (19.8%, 199), are generally undecided (6.5%, 65), are resistant to engaging (9.2%, 92), or would completely opt-out (3%, 30) of the set of data-sharing scenarios that we presented to them.

This result directs us, and those designing data-sharing initiatives, to consider who makes-up these clusters and why people may respond in this way. Indeed, the existence of these clusters aligns with our previous report[14] in which we relay the difference in use of the NHS contact tracing app across social groups and demographics. Bespoke data-sharing initiatives and methods for communicating their design could be developed by understanding which social groups or demographics are most vulnerable to either being dissuaded from, generally undecided about, or resistant to data-sharing and why. Further, an alternative to data-sharing initiatives that are consistent nationwide would be many local versions. Inspiration can be taken from the many local authorities that implemented bespoke services for addressing the various ramifications of COVID-19[1], their effectiveness reflecting knowledge and established relationships with the local communities.

A final recommendation for the design of data-sharing initiatives is to provide some options for how much data detail to share.

The answers to our Data Detail Slider questions clearly illustrate a diversity of willingness regarding how much data-detail to share. We have found that all the attributes influenced how much detail participants are willing to include in the data that they share. Also, the different patterns in our survey data evidence that the influence of these factors differs when sharing Medical data and Mobility data. The complexity of this decision-making indicates that when designing a data-sharing initiative it would be difficult to identify an amount of data-detail that the majority of the public would be comfortable in sharing.

Surveying current COVID-19 data-sharing initiatives, it seems that the dominant approach is 'all-or-nothing' (with 'all' referring to the specific data that the data-sharing initiative wishes to collect, rather than all a person's data, of course). Thus, if someone was concerned about the amount of data-detail that a data-sharing initiative requested from them, their options are limited to engaging regardless or not engaging. Therefore, giving individuals the ability to choose between several 'levels' of detail in the data that they are sharing would allow them to engage with the data-sharing initiative in a way that they are comfortable with.

The data-detail levels would have to be appropriate for addressing the purposes for data collection without collecting more data than is necessary. Further, justifying each data-detail level, and contrasting them in terms of what additional insight or learning the data-sharing initiative can gain if one level of data-detail was shared compared to another, would also allow individuals to make informed decisions about data-sharing that are based on a greater understanding of the impact that their contribution will have.

FUTURE WORK

The analysis reported herein merely scratches the surface of this dataset and the insights that we could gain. Our initial next step would be to further interrogate the data from each of our question types. For example, our analysis of the Willingness Likert Scales does not currently incorporate what the attributes of the data-sharing scenarios were. On the few occasions that the participants in the 'Undecideds' cluster did say they were 'Willing' to engage with a data-sharing scenario, what were the attributes that persuaded them? We could also incorporate results from the cluster analysis into the modelling of the Data Detail Slider data. Since it appears that participant decision-making differs when considering the amount of detail to share in their Medical data and their Mobility data, we could compare participant's cluster membership across the Mobility data and Medical data slider answers.

Afterwards, the next step would be to incorporate the participant demographic data, and the perceptions and experience of COVID-19 data, into our analysis. By doing this we can ask whether these factors influenced our participant's willingness to share data. Prior work has found that there are differences in attitudes to data uses across demographic groups[15], and the mounding evidence of COVID-19's disproportionate impact on demographic groups[16,17] further motivates this investigation.

Notably, we will assess the demographic make-up of the 7 participant clusters that we have identified. Knowledge that a cluster is dominated by a certain demographic would inform our hypotheses for why that cluster's answers patterned in a certain way. After identifying clusters of particular interest, we can invite the participants in these clusters to complete an additional survey, or be interviewed, to investigate the connection between their social background and their willingness to share data. This knowledge can then be utilized to design and communicate the design of data-sharing initiatives to address the concerns of those who are currently less engaged.

CONCLUSION

Our findings from this initial analysis of our survey data re-emphasise how complex decision-making around data-sharing can be, as has been identified in previous work. [15,18] Further, while we cannot rule out that a global pandemic has no impact on this decision making, these findings clearly evidence that the urgency of such a situation does not lead to the public surrendering their data with no concern. Thus, our work offers implications for the future design of data-sharing initiatives that aim to manage public health during a pandemic. Further, considering the Government's intention to continue and potentially increase data-sharing practices post-pandemic[19,20], our research provides important insights into the public's reaction to and engagement with such data-sharing activities and has implications for their design.

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